

Governor's Commission on Mental Retardation

Public Hearing: Issues Affecting Individual's with Mental Retardation

*Report from the Commission's Public Hearing held
Tuesday, November 14, 2006 at Worcester Public Library*

Public Hearing: Issues Affecting Individual's with Mental Retardation

The Commonwealth of Massachusetts

GOVERNOR'S COMMISSION ON MENTAL RETARDATION

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Introduction

I feel like I am a part of the team, and that is how everybody should feel no matter how disabled they are.

(J. Feldman, consumer)

The Governor's Commission on Mental Retardation was established as part of a final court order issued by Federal Chief Judge Joseph Tauro in May 1993, ending a 20 year-old class action lawsuit against the Commonwealth of Massachusetts.

In order to continue the progress made under the court's jurisdiction and to demonstrate the Commonwealth's commitment to quality services for all its citizens with mental retardation, the Governor's Commission on Mental Retardation was created.

One of the mandated purposes of the Commission is to inform the public, as well as those at the highest levels of state government, of how the Commonwealth can improve its services to citizens with mental retardation. The Commission is able to meet this mandate by conducting public hearings or other educational forums. The Commission may convene a public hearing or other educational forum to examine and review a particular area of *systemic* concern regarding the quality and well being of the Commonwealth's citizens with mental retardation. Conversely, the Commission may convene an *open public forum* which does not prescribe an identified public policy issue and allows the public an opportunity to provide commentary, advice, recommendations, criticisms or commendations regarding the Commission or the "state of the state" regarding services to citizens with mental retardation or other disabilities.

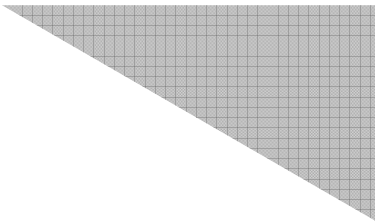
On Tuesday November 14, 2006 the Governor's Commission on Mental Retardation convened an *open public hearing* at the Worcester Public Library in Worcester Massachusetts. Forty-five (45) participants attended the open public hearing, seventeen (17) individuals testified and three (3) individuals provided written testimony. Alfred. A. Gray, Jr. Esq., Vice Chair of the Commission served as the moderator.

This report summarizes the issues identified during the open public hearing and provides recommendations for systemic improvements.

Overview

The Governor's Commission on Mental Retardation convened an open public hearing on Tuesday November 14, 2006 in Worcester Massachusetts to allow all system stakeholders—self-advocates, parents, professionals, providers and public officials an opportunity to provide feedback on obstacles, solutions and recommendations for system improvements. The Commission was interested in soliciting the candid opinions, insights and questions from the public at large regarding such relevant issues as employment, housing, day or vocational programming, recreation and leisure activities, family support, transportation, children's services, aging or other related human service areas.

The Governor's Commission conducts quarterly meetings in Boston and determined that an open public hearing convened in Worcester would provide a unique opportunity for stakeholders residing in Central and Western Massachusetts.



We thought it would be beneficial to hold public hearings in various locations throughout the state to hear from individuals as to what their concerns are, what their suggestions are, any comments regarding the Department of Mental Retardation, the Governor's Commission or things that they would like to see change.
(A. Gray, Vice Chair GCMR)

The ground rules utilized to guide this hearing were articulated by the moderator and helped the hearing progress smoothly and efficiently. Audience members who volunteered to provide oral testimony were asked to provide testimony that was limited to three-five minutes and were encouraged to keep remarks focused on systemic issues such as young adults leaving special education and transitioning to adult services who are turning twenty-two. Participants were reminded that the Governor's Commission is an independent external oversight body comprised of 13 volunteer members who are not permitted to address individual concerns in this type of forum.

The audience members represented a wide spectrum of key stakeholders including parents, self-advocates, family members, interested citizens, advocates, professionals and clinicians. The overwhelming response of participants was quite positive and many individuals thanked the Commission for venturing out "beyond 128" and encouraged the Commission to continue to listen and learn from those who are at the 'ground level' and enthusiastically supported the concept of "open public hearings" and other educational forums conducted in various settings across the Commonwealth.

Testimony from the Public Hearing

After 36 years of fighting for services I am getting tired, but I have no recourse but to continue to be a voice for Denise, and others that need services, such as community residence, employment services, family support, turning 22, and people with Autism that need additional support.

(L. Cournoyer, parent)

The testimony provided at the hearing was delivered by parents, self-advocates, family members, public officials and concerned citizens with much passion and conviction. Commission members were impressed by the candor and fortitude of speakers to provide oral testimony about their private struggles to maintain a high quality of life for their sons and daughters.

The testimony delivered focused on four main areas:

- Budget reductions;
- Adequate salaries for direct care employees in community settings;
- Available and efficient transportation to day or employment settings;
- Improved collaboration among state agencies, specifically DMR and DOE.

Budget Reductions

Several speakers voiced their dismay and anger at the recent 9c budget cuts targeting human services.

In a just humane society we should be able to provide for all of our citizens and most importantly we need to provide for and protect those who cannot advocate for themselves.

(C. Brown, parent)

It is interesting to note that Governor Romney under Massachusetts General Laws Chapter 29, Section 9c enacted a series of budget reductions that totaled approximately \$425 million dollars. These reductions took effect immediately and had significant negative implications for services and supports within the secretariat of human services.

MGL Part I. Administration of the Government

Title III. Laws Relating to State Officers

Chapter 29: Section 9C Deficiency of revenue

Whenever, in the opinion of the commissioner of administration, available revenues as determined by him from time to time during any fiscal year under section 5B will be insufficient to meet all of the expenditures authorized to be made from any fund, whether by appropriation or distribution, he shall within 5 days notify in writing the governor and the house and senate committees on ways and means of the amount of such probable deficiency of revenue and the governor shall within 15 days after such notification, reduce allotments under section 9B and submit in writing a report stating the reason for and effect of such reductions.

These cuts were announced **four days** prior to the public hearing conducted in Worcester.

Many parents indicated that they changed their testimony in light of the recent budget reductions and implications for service decline. They felt compelled to tell Commission members of the need to restore these monies and the need to cite their displeasure with

I see you Commissioners as a conduit to the Governor, and ...please convey that I am very sad and very angry and remind him that at 7:00 a.m. when I am trying to get my son on the bus, he has multiple disabilities, trying to get a disabled child fed and braces put on for the bus at 7:15 you can tell the governor that I often think of him and what he is doing, while someone who is approaching social security age is lucky to have a very cheerful child to get him ready for his day.

(M. Mayo, parent)

the recent actions of the administration. The Department of Mental Retardation was targeted to receive approximately \$9 million in reductions. These reductions affected such services as transition supports for individuals turning 22, community day and employment supports, residential supports, the Boulet (waiting list) settlement agreement, respite and family services and autism services. The numbers of individuals affected is projected to be quite significant and family members were notably concerned. Many parents indicated that without these “planned supports” their sons and daughters could possibly have to stay home in unsupervised and unsafe settings and many parents would have to stay home from their own jobs to accommodate these new situations. Consumers and families decide upon relevant service options as detailed in Individualized Service Plans and develop their yearly schedules based on service appropriations articulated in budget documents received after the budget is signed in June. Provisions are not made for reductions in expenditures and supports suddenly enacted in November.

Adequate Direct Care Salaries

In my opinion the most important and difficult challenge that service providers have is the ability to attract and retain capable and committed individuals to work with the DD. It has been our experience that the folks providing direct care to my son Tim and others find the work fulfilling, rewarding and worthwhile. They certainly are not in it for the money.

(T. Cullinane, parent)

The most striking concern raised by almost all individuals who testified was the need to ensure adequate and competitive salaries for direct care employees. Direct care employees are the lynchpin in any community residential and day setting. The network of supports and services that comprise the system of community care for the state’s most vulnerable citizens is being severely compromised by a lack of direct care staff that is adequately paid. Substandard wages, in a field with limited upward mobility and demanding work schedules, have led to high turnover and ongoing vacancies among direct support staff.

If we care about the individuals that we are serving we need to hire and continue employment for staff that we can get... The Governor has said that the salary reserve has been recalled, and that it will not be implemented. We have worked for it for like ten years or something and we finally have gotten it and now it may not be implemented. I think somebody really seriously needs to look into this.

(J.Cusick, parent)

As part of the 9c budget cuts, Governor Romney cut \$28 million for a purchase of service rate increase that was targeted to direct care employees working in community programs that service the developmentally disabled. Front line direct support staff in community developmental disabilities services continue to be among the lowest paid human service workers in the state. Many of these individuals have earnings which place them near the federal poverty level and often have to work extra shifts or other jobs to earn sufficient funds to maintain a decent standard of living.

All of the staff at Tim's program must work lots of overtime, and many have second jobs. This usually creates a burnout situation or in fact staff turnovers and I can tell you there is nothing more disruptive to the folks that are being served then to have staff turnovers.

(T. Culliane, parent)

Families indicated that there is nothing more damaging to a consumer's growth and development then frequent staff turnover. Relief, temporary and frequent new staffing interrupts the continuity of care. Individuals are less likely to respond positively to staff they do not know. Additionally, under skilled and inexperienced workers require extraordinary supervision, direction and training to be effective. Many families worry about the safety of their loved ones during frequent episodes of staff turnover.

What happens to all the people? The average staff pay is about \$10 an hour. Could you live on this? Many of our staff work two and three jobs to make ends meet... How many years will we have to continue to ask and plead for larger increases — substantial increases in salary to make a difference in the staff paycheck so that the individuals that we love will not be at risk?

(L. Cournover, parent)

Families also indicated that there are many individuals with disabilities without parents or advocates to speak on their behalf. They are relying totally on direct care staff to ensure that their lives are of high quality and without incidents of concern.

These people are being mothers to individuals that they care for, and doing much more than that, and yet we are asking them to continue to work at very poor salaries. They often use this as a stepping stone to go on to something else and the individuals that they are caring for develop relationships with them, and then they leave and it is very difficult.

(J. Cusick, parent)

Many individuals testified that direct care staff needs to be provided with ongoing career incentives, career ladders and other certification programs that encourage and entice young professionals to choose this career path.

I'm sure you can imagine how hard it is for a single mother with a few children to live on a salary of about \$20,000, a year and no hopes of advancement; this is what she is being paid out in the community.

(M. Mayo, parent)

There is a need to market the human service industry as a career path. There is currently no cultural perception of the direct support role. Families indicated the need to link wage enhancement to skill development and develop career paths linked to education and training. Currently, direct care staff must obtain a basic competency level in a variety of essential areas including but not limited to health and safety such as first aid, CPR, medication administration, fire safety, abuse and neglect reporting as well as an orientation to human rights, DMR regulations, individual support plans, community integration and agency mission and values. These are just a sampling of the minimum training requirements needed. Many individuals require direct care staff to obtain additional specialized training, education and expertise in order to provide a safe, nurturing and thriving living environment. Compensation levels which include these additional training and educational requirements should be developed to ensure a more respected and fairly compensated career choice.

Available and Efficient Transportation

I think the public forgets that adults with special needs can't drive and to get to work—to and from jobs they could have, they can't because of the lack of transportation.
(M. Donoghue, parent)

Many individuals testified that transportation is often the key ingredient to accessing community supports. “We have a great park here, and they offer educational programs that teach them how to vote, but they can't get there.” Inclusion is the new lexicon within the human service system however many programs and activities are not accessible to young adults for lack of available transportation options.

We need more money for transportation; more disabled people should be working. I mean I started right from the bottom and worked up.
(J. Feldman, parent)

Consumers testified that even when transportation is available there are often problems with on time performance, and consistency of transit for daily employment venues.

I am here about transportation issues and I would like to see some changes in that—not just for the city but for the state too. They have buses running late, and they don't show up when they are supposed to so... a lot of people like myself have problems that they get stranded waiting for a bus and it never shows up and that is not right. We should all be treated as equals.
(F. Seeley, consumer)

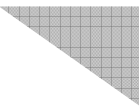
Families and concerned citizens also commented on the lack of public transportation in remote towns in Central and Western Massachusetts and the need for better coordination

among state agencies and regional transit authorities to assist consumers. Transportation is not only critical to ensuring consumers access to employment options, but necessary to ensure that consumers get to medical appointments and other health related appointments and essential social and recreational activities.

In September, 1995 the Governor's Commission on Mental Retardation conducted a public hearing on Transportation services and one of the findings revealed that *"employment opportunities are tied to people's transportation rather than the needs of the employee or the employer."* The testimony provided at today's public hearing did not alter this finding in the year 2006.

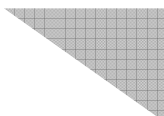
Improved Collaboration among state agencies

The fourth theme articulated by several individuals concerned the need for better coordination and collaboration—most notably between DOE and DMR. Several families and individuals testified about the difficulty in transitioning between DOE and DMR. There is often fear, conflict, uncertainty and worries expressed by many families when their sons or daughters turn 22 and leave the special education system and transition into the adult service system.



If the school system and DMR could have met his needs as a younger child he would more likely be at home, not costing \$130,000 to educate every year.

(E. Farwell, parent)

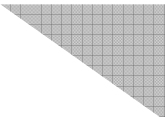


My daughter has been in the system since birth and yet when she turned 22 I was told there was no money for transition for her and that it was not guaranteed. There should be some degree of fairness in the system so that young adults have the supports in the form of funding and teaching in order to learn and to live independently as much as possible and find meaningful work.

(C. Brown, parent)

Families spoke about the need for flexibility and equity in developing supports for these young students as they transition to adult services. Families have been exposed to a new set of operating principles as they develop whole life planning for their loved ones. Empowerment, self-direction and self-advocacy are the benchmarks for these families. Families want to work with agency administrators and support staff in a more transparent and equitable fashion.

Families want to be considered an integral part of the planning process in all stages of development.



I will have to have a lot of flexibility to make sure that my son has the life he deserves, and with the limited availability of turning 22 funding, I need to have the flexibility and the support to live our dream, my son's dreams.

(T. Wheeler, parent)

Families indicated that they are not aware of what the options are, what is available or what they can get as the turning twenty-two process unfolds. There was also much discussion about equity and parity across the Commonwealth.

I believe that if I move from Western Massachusetts to the East, I should be able to get the same type of services and have the same flexibility that I receive now.

(T. Wheeler, parent)

The testimony presented at this hearing reflected much positive support and encouragement for the Commission, DMR and other key stakeholders. Families, consumers and other concerned citizens spoke passionately about several systemic areas in need of reform and were confident of the Commission's ability to initiate discourse and identify strategies for reform.

Recommendations

Members and staff of the Governor's Commission on Mental Retardation were heartened to find that participants were pleased to have been afforded an opportunity to comment on issues regarding the current system of service delivery. As an independent external oversight body, the Governor's Commission on Mental Retardation is charged with ensuring the Commonwealth's commitment to quality services for all citizens with mental retardation. The Commission also takes great pride and acknowledgment in identifying issues that should be reviewed for further consideration and action.

Specifically, the Governor's Commission on Mental Retardation recommends that:

- EOHHS, DMR, ADDP, and other key stakeholders continue to work with members of the legislature and the Governor's office regarding the establishment of an annual cost of living adjustment for direct care workers. The annual base salary of direct care workers must be raised in order to be minimally competitive in the current labor market and to provide a fair wage for direct support workers.
- GCMR work with the Alliance for Full Participation on the establishment of a Massachusetts Chapter of the National Alliance for Direct Support Professionals. A Massachusetts chapter would provide direct support professionals with an opportunity to bring this important agenda to the forefront in Massachusetts, build leadership skills, and gain a voice in issues affecting direct support professionals.
- DMR work with the GCMR and other key agency stakeholders to conduct regional forums on identifying and examining issues regarding transportation for consumers. Transportation should be a support service that assists all consumers in getting to and from an employment setting. Transportation should not be the barrier to employment supports. The goal of these forums is to identify system impediments and develop strategies for change.

- DMR continue to work with GCMR, specifically the subcommittee on transition to improve the consistency and amount of information available to families regarding the turning twenty-two process. Representatives from DOE should be included in future planning processes to ensure greater collaboration and cooperation.

The Commonwealth has undergone significant change and significant growth in the development and delivery of services for individuals with mental retardation and other disabilities. It is incumbent upon all stakeholders to support the momentous advancements and refocus their energies on areas that are in need of review. Support for adequate compensation, benefits and credentialing of direct care staff needs constant vigilance, examination of the vast transit systems across the Commonwealth and their ability to serve constituents with disabilities requires a renewed focus and strengthening the bonds between critical agency partners regarding the turning twenty-two process and transition is both necessary and immediate.

The Governor's Commission on Mental Retardation stands ready to work with executive staff, agency staff and policy leaders within our great Commonwealth to begin to address these challenges and design system improvements that will address all families in need.